

**IMMUNIZATION REGISTRY FOCUS GROUP STUDY**  
**October 19, 1998**  
**English-speaking Mandarin Chinese, Higher Education**  
**Pasadena, California**  
**Moderator: Susan Chow**

**SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE**

**I. Prevention**

Parents are concerned about sinus, amonia, allergy and hepatitis

**II. Immunization**

***A. Reasons not to get vaccinated***

- Ignorance, illiterate, young mothers do not know how to take care of a child
- Parents not responsible for their children.

***B. Reasons to get vaccinated***

- Care and concern for children
- Do not want children to get sick
- Needed by schools for enrollment

***C. Ways parents are reminded of vaccine schedule***

- Through family doctors and schools
- Some parents mentioned that their children were born in Taiwan and the hospital there provided them with a vaccine schedule which they still use in the U.S.

***D. Methods of easier tracking***

- No other suggestions were made other than having a schedule.

**SECTION 2: IMMUNIZATION REGISTRIES**

**I. Initial reactions to the idea of a registry**

- Very positive
- Convenient for parents not having to go back to get immunization information from doctors when needed for school.

## **II. Content of the registries**

There were some questions about who might maintain the information in the registry (i.e. all doctors). The respondents wanted to know how the information gets into the registry to begin with. The respondents would like to see a nationwide registry. No one had heard of a similar type of registry before.

### ***A. Initial reactions to the type of information typically in a registry***

- They felt that it contained basic information that is expected to be found in such a record
- No problems with any part of the information.
- One person questioned why only the mother's name is included.

### ***B. Reactions to include home address and phone number***

- Half the participants did not mind.
- One woman expressed strong opposition to including the home address for security reasons but it was all right to include the home telephone number.

### ***C. Reactions to including parent or child Social Security number***

- Strong opposition about including Social Security numbers because so many things are connected to that number such as tax returns
- Poses security risks should someone get access to the number
- One man saw it as a positive use to help identify the record because you can change your name and address but not your Social Security number.
- Most did not object to including the child's Social Security number. They wondered why it is needed in such a registry. They questioned what the connection is between the two?

### ***D. Reactions to including healthcare members enrollment (WIC, MediCal numbers)***

- There was no reaction to this question probably because no one belongs to these programs.
- One woman said she did not see a real connection between having these numbers in an immunization registry.

## **III. Access**

### ***A. Who should have access***

- Parents
- Doctors (including other health providers)
- School administrations

***B. Who should not have access***

- Anyone outside of the above three groups should not. Respondents did not see any reasons why groups outside of the above three would even need the information.

***C. Reactions to idea of linking registry by computer to other health information systems***

- Most respondents saw it as a positive if by linking the systems it could further the health of their children.
- One man was concerned that the information may be abused depending on how it is used.
- It was all right for researchers to have access except they did not want to be bothered by calling them.
- There was strong opposition to having health insurers linked because they are too commercialized and they make money by getting this information
- The registry should be strictly for the use of the parents to maintain the health of their children.

**IV. Consent and inclusion**

***A. Reactions to “opting out” option***

- There was a mixed opinion about this option although no one wanted to “opt out” because they felt so positive about the registry in the first place.
- A couple of women did not like it because of the assumption they were too busy to respond and would ignore the notification. They mentioned that they might throw it away as junk mail.
- One woman said she would like to be notified more than once. She mentioned that she liked the respect that someone would ask first even though she agreed that the registry is a good thing to be in.
- This option would probably get more people involved which would improve the overall health of the population.

***B. Reactions to “consent” option***

- Not too much reaction toward this policy
- Generally a negative reaction because this would probably result in more people not getting into the registry and therefore not get the immunization information that is so needed for their children.

***C. Reactions to “automatic” option***

- The automatic option was supported by most because an immunization registry is needed by everyone to keep their children healthy
- This would force everybody to be in it
- One woman did express the need for people to have a decision one way or the other.

## **SECTION 3: WRAP UP AND CLOSING**

### **I. Most important benefit(s) of registries**

- Have a tracking system for parents who are busy or those who do not know English
- It is convenient to have a complete record available for schools
- Good for health of children
- Not too concerned about children getting immunized more than once for the same vaccine, probably they felt that responsible parents such as themselves would never make that kind of mistakes.
- When probed, most agreed that such a registry could ensure a child who has a medical condition not be given vaccine that could be potentially harmful when probed, but didn't express any strong feelings.

### **II. Greatest concern(s)/biggest risk(s)**

- The respondents reiterated that insurance companies should not get access
- They did not understand why law enforcement would even need this kind of information.
- There was a question why the government would want this information and what they would do with it.
- There was no comment regarding the tracking of children or denial of health benefits or custodial issues.
- Regarding denied entry to day care and school; they saw that as good because it would make parents more aware of what immunizations are needed for their children.

### **III. Influence of healthcare provider in decision to participate in a registry**

- Half of them would be influenced by their doctor's opinion
- The others said it depended on what the doctor said but they would rely on their own judgment.

### **IV. Suggestions/comments to people who are responsible for how system works**

*Make the registry mandatory.*

*Limit access of the registry to only doctors and health-related organizations.*

*Do a systematic check regularly to update information in the registry.*

*Add children's blood type.*

*It is a great idea and should have started a long time ago when the first vaccine came into being.*

*Notify parents every year what immunization is needed for their children.*

*Send a form to parents every year to make sure they are responsible to their children.*

*Do best to maintain the integrity of the registry so it is not abused.*

One person asked for more information about the cost of vaccine. She was told to call the County Health Department, Immunization Section.